



NATIONAL FOUNDATION
FOR CELIAC AWARENESS

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Docket Number 2005N - 0279
US FDA
Food Labeling; Gluten-Free Labeling of Foods
Public Meeting of August 19, 2005

Submitted by:
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My name is Alice Bast, and I am the Founder and Executive Director of the National Foundation for Celiac Awareness. On behalf of all Americans who suffer with celiac disease, I appreciate the opportunity to provide information on consumer understanding of the term "gluten free" and the purchasing practices of celiac patients and their caregivers for today's public meeting on gluten-free labeling.

The National Foundation for Celiac Awareness prepared a short survey which was posted on our website, www.celiacawareness.org, and was e-mailed to support group members around the country. We received informative and heartfelt responses to a set of 7 questions that were developed based on Questions 8, 9 and 10 in the notice for today's public meeting. We will submit their full responses as part of our written comments and I will summarize them here for you today.

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The respondents are educated consumers and spend considerable time and effort educating themselves and researching the contents of the food they buy in stores and eat in restaurants. They rely on the "gluten-free" label and express trust in food manufacturers who have policies not to hide food allergens and gluten. When given a choice, they buy products that are labeled "gluten-free" over those that are not. They are thrilled that food labeling will be soon be improved because it will save time, reduce frustration, and provide a measure of confidence that they and their families are eating foods that are safe.

Following are the questions we asked and a summary of the responses we received.

1. What does the term "gluten-free" mean to you?

The overwhelming response was that "gluten-free" means "gluten-free", that is, that the product contains no gluten from wheat, barley or rye, and related grains. A few mentioned 'above a safe threshold', but in general respondents expressed an understanding that no gluten is present in the food product, either directly or as a result of cross-contamination.

2. How do you identify foods that do not contain gluten?

The primary response was "read the label", followed by: calling and e-mailing manufacturers, food lists from celiac support groups, references provided from medical providers, and the internet. Often people read labels and call manufacturers to confirm, having learned about cross-contamination potential and changing manufacturing practices as hidden sources of gluten. Many mentioned calling the manufacturer while in the grocery store in order to be able to make a safe purchase.

Respondents expressed the need to look for ingredients other than wheat, barley and rye, for example, maltodextrin, modified food starch and other ingredients that contain gluten in reality but not in their names.

Many mentioned the difficulty in eating out safely, because restaurants don't always know whether gluten is contained in the bulk ingredients they buy.

3. How much time do you spend identifying gluten-free foods?

The responses to this question varied. Some folks indicated that now that they are educated and have their lists it does not require much time, others spend 30 minutes or more extra each week reading labels and researching ingredients. Several people said that grocery shopping takes twice as long or more now. It was frequently expressed that they would prefer not to use their cell phone minutes calling manufacturers to confirm ingredients while in the grocery store.

Many have come to rely on the current "gluten-free" label as a time saver, and seek out brands from companies such as Kraft and McCormick who have voluntarily made allergen and gluten information available on their packaging. Many expressed the need for a uniform label so it would be faster and easier to find the information.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Many respondents indicated that they do purchase products that are labeled "gluten-free" if available. They also indicated that they must purchase products that are not labeled, and in order to do so, they must read the ingredient list. Many mentioned the added expense of products that are labeled "gluten-free".

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example, breads, dairy foods, canned vegetables?

Respondents listed items such as: cereals, pancake and baking mixes, breads, deserts, crackers, sauces, frozen meals, hot dogs, sausage, sliced meats, candy, protein bards, muffins, pasta, spices and seasonings, soy sauce, cookies, brownies, waffles, flours, prepared meals, soups, pizza, rice and pasta mixes, corn tortillas, cheeses, margarine spreads, pretzels, beer, gravy mix, pepperoni, chicken and beef stock, donuts, snack foods, dinner mixes, vitamins, pudding, packaged vegetables, gum, mints, toothpaste, nuts, drinks and drink mixes, condiments, salad dressing, and dairy products.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

The overwhelming response was "yes". People indicated that they felt confident that the food was safe for them to eat if it had a "gluten-free" label.



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RE: Comments presented and submitted by Alice Bast, Executive Director of the National Foundation for Celiac Awareness

Full Responses to Gluten-Free Food Labeling Survey

conducted by The National Foundation for Celiac Awareness, August, 2005

As a celiac disease patient or a caregiver of a celiac disease patient,

1. What does the term "gluten-free" mean to you?

Food labeled Gluten-free should have amounts of wheat, rye, barley and oat proteins below levels determined by research to have little effect (perhaps 20 ppm). Some research indicates some Celiacs do react to oats (and perhaps dropped out of the initial studies on oats), plus wheat contamination levels in oats is high.

2. How do you identify foods that do not contain gluten?

Read labels, call manufacturers, get food lists from celiac societies and from celiac email lists, and read labels.

3. How much time do you spend identifying gluten-free foods?

30 minutes/week now since have lists of acceptable items.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

No, it's preferred but I trust many other items.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Cereal, pancake mix

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having

identical ingredient lists?

yes.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I'm very much looking forward to proper labeling.

1.What does the term ?gluten-free? mean to you?

That the product contains NO wheat or gluten

2. How do you identify foods that do not contain gluten?

I and my wife label of every food we buy to see if it contains, wheat, barley, malt or modified food starch. We then reject any product that contains any of these ingredients. Labeling as Gluten free would save us a lot of time and trouble.

3. How much time do you spend identifying gluten-free foods?

About 20> minutes per week reading labels.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled ?gluten-free??

No but we purchase "gluten-free" labeled products if they are available. Otherwise we have to read the label for all ingredients and see if there is a problem

5. If so, what types of packaged foods that are labeled ?gluten-free? do you purchase? For example: breads, dairy foods, canned vegetables?

Everything. Breads and deserts are the most common. Most other products are not currently labeled "gluten-free"

6. Does a ?gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes. I would much prefer to buy products labeled "gluten-free"

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I think that the title "gluten-free" should be reserved for products that are clearly wheat-free. My father is 87 and highly> sensitive. Even a small amount of gluten triggers an upset. I think we should be conservative in what we allow to be labeled 'gluten-free"

1. What does the term "gluten-free" mean to you?

Gluten-free means that a product has virtually no detectible amount of gluten in it and was not produced in a facility where gluten-products were present that could produce cross-contamination in the production or packaging process. Gluten-free also means that none of the component ingredients contain gluten.

2. How do you identify foods that do not contain gluten?

I look at ingredient lists, refer to lists I have accumulated from manufacturers and celiac support groups and reference materials from medical providers.

3. How much time do you spend identifying gluten-free foods?

I spend a considerable amount of time. I can't quantify it, but it is probably 2-3 times more than I spent before my two children were diagnosed with Celiac Disease. I find shopping more time-consuming and difficult particularly if I am attempting to purchase unfamiliar food items, dining out, or shopping away from home. Typically, I have a circumscribed range of food products that I purchase because I have already researched them and feel confident about their gluten-free status. Because of the time-consuming nature of all of this, I tend to shop at only one grocer that caters to gluten-free shoppers. I depend heavily on purchasing products by mail order. If I am traveling, I have to do extensive on-line research in advance to locate grocery stores and restaurants where my children can eat before we travel to a new area.

Dining out is particularly difficult because restaurants often cannot provide ingredient lists for the food items they use in food preparation. They purchase food items in bulk and often the packaging does not provide ingredient lists. Restaurant-grade food items often has unexpected gluten content as well (modified food starch in the sour cream, for example). Meat that has been pre-treated with tenderizer from the manufacturer at a restaurant may have gluten in it. Salad dressing can be a problem and ingredient lists for such things are often not available. It can be stressful, when traveling, to go into a restaurant and have a chef/waitperson be rude or unresponsive. We tend to avoid restaurants in general unless we know they have gluten-free menus for this reason.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Yes. If it is not labeled, gluten-free, then I have already checked with the manufacturer to determine that it is gluten-free.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Bread, crackers, baking mixes, sauces, frozen meals, hot dogs, sausage, sliced meats, candy, protein bars, muffins, pasta, cereal, spices and seasonings, soy sauce, cookies, brownies.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Living with a Celiac Disease diagnosis and contending with a gluten-free diet can be extremely difficult and challenging. My two children encounter countless barriers and obstacles to living normal lives because of the unavailability of gluten-free food alternatives in our community. As I look towards my eldest child turning 18 this year and becoming an independent adult, I have significant concerns about the enormous task that faces him in managing his diet in a world where he must either eat a very circumscribed variety of "safe and approved" foods or else he must be prepared to call manufacturers to research gluten content on his own on a weekly basis. There are great on-line resources available now to identify these foods, but manufacturers are continually changing their ingredients and it is cumbersome to have to always refer to lists and internet sites every time you go shopping. This is a burdensome way to live and it makes Celiac Disease into a disability because of the many barriers individuals with this disease must face. If gluten content was properly labeled on food items, individuals with Celiac Disease could manage their diets and avoid gluten exposure much more easily! Given the increasing diagnosis rate, this seems like an absolute necessity.

1. Gluten free means foods without the forbidden grains and not just those that say wheat free.
2. I identify gluten free foods by reading labels and knowing in advance what is allowed and what is not allowed on by special diet.
3. It is time consuming to identify gluten free products, but the time involved is absolutely essential.
4. My answer is thoroughly gluten free.
5. All of the above.
6. Absolutely.

1. What does the term "gluten-free" mean to you?

The patient cannot eat or drink anything that has a wheat base.

2. How do you identify foods that do not contain gluten?

Read food labels and ask questions.

3. How much time do you spend identifying gluten-free foods?

Not as much time as I should, but I am more aware of the problems that face people who suffer from this disease, since my niece was diagnosed with it.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I read the food labels to make sure there are no wheat based products listed.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

It would make shopping easier because I would not have to read the ingredient labels.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I have noticed in the past year that more products are using the "gluten-free" label. I hope that the pressure will be continued to make sure that all products that are "g-f" will get the proper labeling. This will make it easier for the patient to adhere to forced diet with less stress.

1. What does the term "gluten-free" mean to you?

-to me, it means eating a diet that contains absolutely no traces of gluten (wheat, rye, barley, and oats)

2. How do you identify foods that do not contain gluten?

I usually look at the ingredients. If its a pretty long list of ingredients, I usually just assume it has gluten unless I have already been told it is gluten - free. If the list of ingredients is shorter, I read the list to make sure.

3. How much time do you spend identifying gluten-free foods?

I usually spend around...I don't know...30 seconds to a minute. It really doesn't take that long

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

No, not always. I usually only by frozen meals that say gluten-free

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I buy the breads and the cereals. Also the frozen meals and waffles.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes it does, because i am more confident of the fact that the product IS gluten free

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I think that "gluten-free" should be put at the end of ingredients that are gluten free or it should say "contains gluten" so that it is much easier to read and won't take up as much time.

1. What does the term "gluten-free" mean to you?

No wheat, rye barley or oats, triticale, spelt and a few other grains.

2. How do you identify foods that do not contain gluten?

Read lots and lots of labels! Call and email companies. Check lists of mainstream gluten free products.

3. How much time do you spend identifying gluten-free foods?

I spend hours shopping for food. I go to several stores. I can be seen scrutinizing labels adn even many times calling companies on my cell phone, which I do not appreciate using my minutes, especially if I have to wait. Sometimes they promise to return my call and do not. Very frustrating.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I do get some but not many. No, much too expensive. My son and I are celiacs and it would break our budget. Plus my husband is not celiac and I need to cook "normal foods for him (e.g. wheat pastas).

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Bread and baked products from Whole Foods. Sometimes boxed mixes. and gluten free flours. All are very expensive.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Sometimes, if I have the money.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I would like to have guidelines like some of the companies have now. such as McCormicks and Kraft for example. there are other companies too. They say they do not hide gluten or any of the 8 major allergens. They will state if there is any gluten right on the package.

There are so many questionable ingredients that may or may not contain gluten such as flavors, spices, fillers, HVP, soy sauce (usually wheat based but not always), caramel coloring, etc.

I cannot say enough for these guidelines. I really appreciate the companies that do have these policies. I feel safe with them; but still it is so important to read labels and that is SO VERY TIME CONSUMING!!

I am 27 year old female with celiac disease living in Maryland.

1. What does the term "gluten-free" mean to you?

It means that if I eat it, I can be 100% confident that I will not feel sick that night or the next morning. I run a store, and it does close for the day because something "accidentally" contained gluten:)

2. How do you identify foods that do not contain gluten?

By only looking at brand names that I have been told are very specific about wheat, malt, and sometimes, even "gluten" in their ingredients labeling section.

3. How much time do you spend identifying gluten-free foods?

As long as it takes!!! At least 20 minutes a day!!

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Yes. Therefore, I don't really have the convenience right now of buying many "packaged" foods.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I would buy THEM ALL. Right now all I know of that is labeled is mostly frozen foods and canned goods. I would like to see more popular cereals, candies, ice cream, Uncle Bens rice mixes, etc labeled

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

definitely!!!!!!!!!!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I would also like to see more sauces (bbq, etc) labeled, and salad dressings & yogurts too!

1. What does the term "gluten-free" mean to you?

No wheat, rye, barley or oats, spelt or triticale.

2. How do you identify foods that do not contain gluten?

By reading labels, calling manufacturers about questionable ingredients and e-mailing companies.

3. How much time do you spend identifying gluten-free foods?

I have spent and still spend hours and hours shopping and calling and e-mailing. I do not appreciate having to use my cell phone minutes, having to wait for quite a while at times to get the information I need and sometimes companies are not even open when I am shopping and also do not always return my calls.

4. When you purchase packaged foods do you purchase foods that are primarily labeled "gluten-free"?

I do sometimes, but GF foods are very expensive and would break my budget. I purchase flours, frozen foods at times (expensive and not much too them).

5. Is so, what types of packaged foods that are labeled "gluten-free" do you purchase, for example: breads, dairy, canned veggies?

I buy breads and other baked foods from Whole Foods which they bake in their GF bakery in South Carolina.

Also, I buy Amy's frozen Mac and cheese and some of their other frozen dinners (very expensive). I get these only to have something on hand if need be. My 19-year-old son is also celiac and goes to work while I am still at work and often needs to eat something or even to bring something to eat for dinner at work.

It is very hard to eat out or fast food when one is celiac.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredients?

Not necessarily. I know some products by certain companies, e.g. McCormick's, Kraft's, Tyson's, certain brands of spaghetti sauces, certain brand named hot dogs, etc. which have a policy of not hiding any of the 8 major allergens. So if I don't see anything on the label, I know I am safe. These are products I can buy in the regular grocery stores. I buy regular foods as much as I can because of the cost.

7. Would you like to share any other thoughts about the need for accurate understandable food labeling or your experiences with food labeling?

As I have already stated above, the time-consuming hours of shopping is because of labeling which is not clearly marked with the allergens. People need to see these immediately on the labels. To have the confidence that what I am buying will not hurt me or my son, would be so very comforting, if only all labeling were done in this way. With so very many questionable ingredients and also cross-contamination issues, you can see the problems and the definite need for proper food labeling.

I have lists and lists from companies and also from gluten-free internet sites which I bring in a large canvas bag to the grocery store. This is also very time consuming and if I stop at the grocery store and do not have this bag with me, I cannot always purchase something I might see or need or is on sale, for fear that it might not be gluten free.

I would really, really like to see all food labeling to state any of the 8 major food allergens.

Hello. I have 2 young sons with CD. My 5 year old gets violently sick (vomits, diarrhea) from even a small amount of gluten. My 22 month old just gets an upset stomach and diarrhea. My husband was diagnosed at age 3 (in 1966) with Ulcerative Colitis. He refuses to admit he has CD (and continues to eat alot of gluten) because he says even though both his children have it, his doctors can't be wrong. (He had his colon removed in 1989 so he blames his chronic diarrhea on that)

So, feeding my family is extremely difficult.

1. Gluten-free to me means that no gluten, either by ingredients or cross-contamination exists in the food.

2. I read ALL ingredients very carefully, and because I've educated myself (it took a long time) I pretty much know what to look for (for hidden gluten). If a product says gluten free I buy it without reading the ingredients.

3. I spend a tremendous amount of time food shopping for gluten-free foods for my family. I buy some stuff off the internet & I drive 15 miles to a Health Food Store which stocks alot of GF products. (also spend alot of \$)

4. No

6. Yes

My 5 year old has gotten sick probably 10 times from foods which I thought were GF after reading the ingredients. Obviously they had hidden gluten. His misses at least 1 day of school each time he gets sick.

Proper food labeling is crucial for my son. Even though his condition is not life threatening (ex. peanut allergy) I can't help but wonder if any permanent damage is being done each time he gets sick.

I appreciate your efforts regarding food labeling. Please let me know if I can help in any way.

1. What does the term "gluten-free" mean to you?

It means that the food item contains no form of wheat, barley, oats, or rye.

2. How do you identify foods that do not contain gluten?

By reading the list of ingredients.

3. How much time do you spend identifying gluten-free foods?

Between 15 and 30 minutes during grocery shopping if I have to shop for salad dressings, cereal, or sauces of any kind.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I do look for the "gluten-free" label.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Cereals and breads.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

1. What does the term "gluten-free" mean to you?

Food that is safe to eat. It is very difficult trying to decipher ingredients that do not state "gluten free."

2. How do you identify foods that do not contain gluten?

It's a "best guess" effort. It is very difficult...modified food starch, artificial coloring, caramel, etc.

3. How much time do you spend identifying gluten-free foods?

Too much time!

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Whenever possible, I buy mostly anything that states "gluten free."

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Breads, pizza, soups, desserts.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

It would make shopping a much better experience. There would be no second-guessing. It takes the guess work out of choosing the correct foods and eliminate unnecessary after effects when you choose the wrong item. Labeling stating "gluten free" would be a wonderful thing. Many of Amy's products not clearly state, "gluten free" and I tend to search our her products. Good luck with enabling proper labeling to happen. Thanks. Pat

1. What does the term "gluten-free" mean to you?

No gluten that I can identify.

2. How do you identify foods that do not contain gluten?

Read labels. Look for ingredients that I know contain gluten. I know that I probably miss because I don't know some of the things that I should be looking for.

I do feel safe purchasing items that are identified as gluten-free.

3. How much time do you spend identifying gluten-free foods?

A trip to the grocery store takes me at least twice as long as it use to. Some times it takes longer than that.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Packaged foods that I purchase are exclusively labeled "gluten-free".

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I do purchase breads and other baked goods, and rice and pasta mixes

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

If the item has IDENTICAL ingredients, I would buy the least expensive brand.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling

There are so many ingredients that are not gluten-free, it is impossible for most people to know all of them. Celiac patients that are reading labels looking for gluten in products could easily overlook ingredients, causing undue effects.

1. What does the term "gluten-free" mean to you?

Any food that does not contain wheat, rye, barley, or oats and is made in an environment which precludes cross contamination with above mentioned ingredients.

2. How do you identify foods that do not contain gluten?

Read the label and then call the manufacturer of the product. This can be a very time consuming process!

It is virtually impossible to eat anything at a mall or fast food outlet, unless I've called the chain's headquarters in advance.

3. How much time do you spend identifying gluten-free foods?

Several hours a week.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I am very excited when I see a food is labeled gluten free! This means no further research is needed and we can just buy and eat the food.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

corn tortillas, cheeses, spaghetti sauce, breakfast cereal, margarine spreads, pretzels, cookies, crackers, pasta.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

ABSOLUTELY!!!!!! It means I can feel confident serving the food to my daughter, who is gluten intolerant, and that I don't have to go home and make phone calls to manufacturers to ascertain that the food that looks gluten free really is gluten free.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

It would be wonderful if more foods were labelled. Additionally, it would be fantastic if fast food chains, ice cream stores and other retail establishments were required to label. As it stands now, my 9 year old daughter cannot participate in snacks at school, eat regularly served foods at birthday parties or eat out without research being done prior to the event. This is very upsetting for her. Her quality of life would be improved if it was made common knowledge which products are gluten free and the consumer did not have to spend hours researching products.

1. What does the term "gluten-free" mean to you?

Gluten-free means not having any wheat, rye, barley, or oats in the product. It also means safe from cross-contamination.

2. How do you identify foods that do not contain gluten?

I have several lists of products from celiac groups listing safe foods. I subscribe to a magazine called Living Gluten-Free that has helped me a great deal. I also read labels, and if there is a questionable ingredient, I contact the company directly.

3. How much time do you spend identifying gluten-free foods?

Before going to the grocery store, I check the items that I need, and if it's something I have not used recently, I check in my safe list for recommended brands. At the grocery store, I spend major amounts of time reading labels. My time shopping has doubled since I was diagnosed.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I live in a small town, and two of the grocery stores have quite a few items that are labeled GF in their health foods section. I also travel an hour to get many of the GF things that I need, or I order directly from companies. I also buy many items that are not labeled GF after checking the ingredients listed. Most of what I eat is not labeled GF.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I buy GF cereal, breads, pastas, flour, cake mixes, brownie mixes, bread mixes, soups, cookies, and beer.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

It absolutely does. I always worry about cross-contamination when buying unlabeled products.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I understand that the FDA will soon require companies to list major allergens on the ingredient's list. However, I think that it will only include "wheat" and not the other problem glutens. While it will be somewhat helpful, I really wish that we could convince the FDA about the seriousness of celiac disease and insist that companies include rye, barley, and oats in that list. There are so many questionable items listed in the ingredient's list that it is very difficult to know if I am always eating safely. Many celiacs do not react physically to gluten, so they don't know if they have eaten anything that could harm them. If you need more information, please let me know.

1. What does the term "gluten-free" mean to you?

That there is no wheat, barley, oats or rye in it and it's safe for me to eat; that the manufacturer has ensured that the food is safe for me.

2. How do you identify foods that do not contain gluten?

I buy some foods at a specialty store that sells gluten-free foods; I also read labels very carefully.

3. How much time do you spend identifying gluten-free foods?

This question is a little ambiguous -- do you mean once I'm in the store. I'd say five or ten minutes reading labels.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

No, I would have a lot less to eat if I did that.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I buy bread, crackers, cookies, baking mixes, gravy mix, frozen meals, candy, pretzels

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

It saves a lot of time and effort if you KNOW that the food is GF, rather than having to read ingredient lists.

1. What does the term "gluten-free" mean to you?

Does not contain wheat, oats, rye and barley.

2. How do you identify foods that do not contain gluten?

By careful reading of the ingredients. I do not buy it if it contains something that I am not familiar with.

3. How much time do you spend identifying gluten-free foods?

Since I have been diagnosed for eight years, I am more familiar with what is available but at first, it took a long time to find items that I could eat on the store shelf. For food for myself, I usually shop at MOMS (organic market) or Whole Foods.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

In most grocery stores, it would be difficult to shop and I would have little to choose from if I only purchased items marked "gluten-free." I would be cooking EVERYTHING that I eat from scratch or eating only plain meat and produce - no bakery products such as bread, cookies, or cereals. Thankfully, we have wonderful organic stores that carry these specialized products THAT ARE LABELED!

Perhaps this doesn't specifically answer your question, but I do rely heavily on the "gluten-free" labeling, unless the ingredients list is very straightforward.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example breads, dairy foods, canned vegetables?

Hormel pepperoni, Breads, cereals, Thai Kitchen soups and meals, cookies, crackers, pasta and cake mixes.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

YES, ABSOLUTELY!!!!!! The label is my "security blanket"!!!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling? It might be difficult for someone who does not have to follow a special diet to identify the many problems that we face in shopping for our food -- having to go long distances to shop, having to pay about double for food items, facing the uncertainty of figuring out ingredients, and finding food that is appetizing and appealing as well as having a variety of foods to choose from. I certainly didn't understand it before I was diagnosed. It is not the same as someone who makes a choice to eat vegetarian, organic or nonorganic, or to be on a diet to lose weight, or the food fad of the month or according to their likes or dislikes, but it is a critical issue for celiacs (it could be a life or death matter) and there is no choice involved. WE NEED ALL THE HELP THAT WE CAN GET!!!!!! Thanks for your advocacy!!

1. What does the term "gluten-free" mean to you?

Does not contain wheat, oats, barley, rye, MSG (unless I know where it's from), or modified food starch (unless I know where it's from).

2. How do you identify foods that do not contain gluten?

Reading labels carefully and asking questions (in restaurants). I also look for allergen information on labels, but it rarely exists.

3. How much time do you spend identifying gluten-free foods?

Not much, now that I know what to look for. It really depends on how easy the label is to read. But I would spend less time if gluten were listed as an allergen!

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

No, because so few are labeled that way. I always check ingredients.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

I purchase pasta, baked goods, chicken and beef stock, etc. that are labeled "gluten-free".

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely! It is easier and makes me feel safer.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I recently got back from Brazil, where, by law, virtually ALL packaged foods are labeled "contains gluten" or "does not contain gluten". It was MUCH easier to eat here than in the U.S. I even saw a bottle of water that said "does not contain gluten". We could (and should) learn a lot from Brazilian food labeling laws! The biggest problem is with products that contain MSG and modified food starch, as they do not state where those ingredients come from. Thus, I avoid all such products, even though I might not need to.

Nancy, if at all possible, I would like to present remarks on this subject at the hearing. Would be happy to work with you on all of this. Met and spoke briefly with Alice at patient info day at U of MD. Also, Nancy Fellini is very familiar with my products (Grandma Whimsy's Cupboard - especially my flour), as is Pam Cureton and Dr. Fasano, who claims they are THE best, and they would probably attest to what we are doing here in MD. Will be working with Pam King, Pam Cureton and Dr. Fasano relative to GF foods in hospital, etc.

I did participate in the initial FDA public hearings in DC and submitted a simple approach to labeling and addressing the issues of non English speaking consumers, children, and those with limited eyesite. It was quite doable. Not sure if any of the ideas or graphics presented were used. We were told prior to the hearing not to mention gluten at that hearing, but many of us managed to get something in our presentations anyway. FDA would have a lot more insight into gluten if they had allowed participants to address the issue along with wheat. I had conflicting comments from the committee members in private discussions re: GF and how the topic would and would not be taken up. Not good.....

I am a food manufacturer and some of my thoughts are included below. I am also a biopsy diagnosed celiac with other foods on my avoid list besides gluten. I have a background in science and environmental science and am alarmed at the multitude of

additives, gums etc. that are being included in foods today. I began my quest to provide good GF foods that were affordable and accessible and safe by keeping all ingredients and allergens to absolute minimum in any products I make for myself and others, with double assurances to folks who had to have 100% GF, allergen free products. It is again, doable.

At age 66 I am healthy because of following a diet of fresh foods, careful selection of what I rarely consume prepackaged, and more common sense than anything. My list of safe foods differs from experience from some advocates of certain foods. I always encourage people to read labels beyond GF. If there is a long list - especially of items you cannot pronounce - you have a choice GF or not. Putting healthy foods into your body will bring health. Putting chemicals and unnecessary additives into the body will not.

General health is as important a focus as CD and the GF diet. We are what we eat, and I want to know what I am eating - Then and only then can I make a wise and conscious choice about what goes into my mouth. Let me know if there is any collaboration between your work and my work - that can make a greater impact on those listening to the participants. It does matter what gets said how it gets said, and who says it - it does make a difference whether it is "heard" or just spoken words that do not take on any meaning for the listener..

My graduate work in environmental science and communication centered on Citizen Public Participation, My Instructional design work focused on development and effective education and training practices. Perhaps these skills and my 21 years as a diagnosed celiac patient and almost 10 years now in the field of producing quality GF foods will lend itself to this upcoming event. I believe I can contribute some very insightful information and concerns and will do so.

1. What does the term "gluten-free" mean to you?

If this is on a label, I nutritionist has made this determination and I feel comfortable eating this product.

2. How do you identify foods that do not contain gluten?

Reading the labels, but too many foods use unknown terms or terms such as coloring & flavor additives.

3. How much time do you spend identifying gluten-free foods?

It adds an hour to shopping time.

Restaurants are a significant problem- asking for gluten free meals is not usually understood.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Yes that is a comfort zone.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Mainly bread products.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes --absolutely!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Wheat free does not help --Gluten free does.

1. What does the term "gluten-free" mean to you?

Food that is not contaminated with gluten found in wheat, oats, barley or rye. My boys are sensitive to oats so I include oats in my definition. I usually don't worry if the label says it contains no gluten though it was manufactured in a facility that also processes wheat products since these products, so far, haven't posed problems.

2. How do you identify foods that do not contain gluten?

I read the labels and look for the absence of obvious ingredients labeled, "wheat, barley etc." but I also avoid foods that are labeled with starch, maltodextrin, dextrin, and modified food starch unless the label specifically notes they are corn-derived or another gluten-free derivative. We try as best we can to avoid foods that contain red dye 40 since it seems to have given one of my sons problems in the past.

Occasionally I hear about a brand, like Ranch, from an internet bulletin that indicates it is safe though one wouldn't know from the label.

3. How much time do you spend identifying gluten-free foods?

More than I would like. Any time I am looking at buying a new food item it is a concern whether it is gluten-free.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Ideally this would be great but most foods are not labeled so we stick to whole foods, not processed and this eliminates many problems for us.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Hormel pepperoni, Lay's Stacks, Envirokids cereals

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

absolutely, I would definitely pick the gluten-free product

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Accurate, understandable food labeling definitely needs to improve in our country. I have an easier time eating overseas than I do in America.

I am very intolerant of corn as well as gluten. If you think it is difficult to determine if something is gluten-free just try living corn- and gluten-free, it is very difficult. I dread ever having to go to the hospital because most medicines use corn derived products as their fillers and I am sure IV drips do as well. I currently have not identified a multi-vitamin that I can tolerate. Corn contaminates everything including barbecue sauce, iodized salt, Mary Kay make-up and meat treated with broth or dextrose. It is very frustrating!!!!

I spend so much time reading labels as I am not only Gluten Free, but corn free and lactose and eggs and soy free....labeling is very important to me...I always double check items even if I have used them before, especially, if the labels are changed. Last summer I ran into a problem without reading the label from some chicken I had previously purchased and got sick for two months...then I found out after reading the label that they had added corn flavoring...so we have to not only read labels but be aware of changed packaging..

What does the term gluten free mean to you?

For a long time, I thought gluten-free meant exactly that - that the food had absolutely no gluten in it. It never occurred to me that a food labeled gluten-free could possibly have any gluten in it. If I read the ingredients, there was nothing that could possibly contain gluten. I wasn't really thinking about cross-contamination of gluten-free foods. I really thought gluten-free foods were the safest for my daughter. Since then, of course, I have learned a lot more about what the term means. It throws me a bit to think that one of the biggest threats to her might be a food that she eats consistently, every day, in rather large quantities in part because it is a gluten-free substitute for "regular" foods. But I try to be realistic when assessing what gluten free means and how much of a threat a regularly consumed gluten-free food is. I am comfortable that my daughter can safely eat the gluten-free food that is available.

How do you identify foods that do not contain gluten?

I read the ingredient label or I go by a label that says gluten-free on the package, followed by a reading of the ingredient label. I do not rely on lists of gluten-free food anymore.

How much time do you spend identifying gluten free foods?

Even 13 years after my daughter's diagnosis, I would estimate that about 30 percent of any shopping trip is spent reading labels to determine if something is gluten free. That means if it takes me 2 hours to shop, about 40 minutes is devoted to reading labels.

When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled gluten free?

No, I also purchase regular foods from the grocery after reading the label and determining that they are gluten free. I do rely on certain products that are labeled gluten free, like bread, pasta, cake mixes etc. Mainly I buy the things that could not be gluten free unless they were specifically made to be so.

Does the gluten free label influence your purchasing decision when you have a choice among products having an identical ingredient list?

It is always helpful to have a gluten free label. For example, Uncle Ben's white rice is labeled gluten free. I can tell it is gluten free by reading the ingredients, but its just nice to have it be made so simple when managing the diet can be complex. Plus I think it helps make you feel less isolated and odd when a mainstream product carried in a regular grocery is labeled gluten free.

Other thoughts?

What I mainly want from a food is availability for my daughter. What I really want is food companies that will go the extra step to make a product gluten-free if it's possible. For example, rice cereal makers who would be willing to use a flavoring other than barley malt that renders a product that should be gluten free unusable. But I suppose I'm dreaming. What I want from labeling is a clear picture from the label as to what is safe. I don't want a label that makes me think something might not be safe when it actually is, for example a product that contains citric acid made from wheat when, in fact, citric acid made from wheat is still gluten free. I don't want a label that says a food contains wheat when the amount is too small to cause damage. I don't want a label on something that contains spelt that says the product is gluten free. I would like a gluten free label that holds companies responsible for testing their products to be sure they do not contain amounts of gluten that are over acceptable levels. (currently thought to be somewhere around 20 ppms)

1. What does the term ?gluten-free? mean to you?

It means that the ingredients in that food item are not made with any wheat, oat, barley or rye

2. How do you identify foods that do not contain gluten?

I read the ingredient label and often call the manufacturer to be sure. If and when I call the manufacturer I also question whether gluten containing ingredients are used in the same factory or processing line.

3. How much time do you spend identifying gluten-free foods?

Too much!! For every new item I probably spend approximately 10-20minutes.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled ?gluten-free??

It is about 50/50.

5. If so, what types of packaged foods that are labeled ?gluten-free? do you purchase? For example: breads, dairy foods, canned vegetables?

Bread, donuts, pizza crusts, cookies, crackers, dinner mixes (ie- hamburger helper style), pasta, snack foods, vitamins, cereal

6. Does a ?gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

YES!!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I understand that although some labels say gluten free that are not actually. How is this?? I love that some packages of UTZ chips now say gluten free on the back label under the ingredients. Although I have been doing this for my daughter for about six months now I still get confused and am afraid that I am contaminating her. (Her numbers are still not in the normal range, although they are significantly lower). Clear labels need to be available so that individuals with allergies do not have to worry and work ten times harder than those with peanut allergies, etc to ensure a strict diet.

1. What does the term "gluten-free" mean to you?

That there is no chance that this product contains or has come into contact with gluten.

2. How do you identify foods that do not contain gluten?

I read the ingredients on the package and have to rely on the company's honesty in printing chances of cross-contamination. We also rely on the CSA product book and I do email companies on my own and ask for lists.

3. How much time do you spend identifying gluten-free foods?

Several hours per week are spent on making sure we are only buying/using gluten-free foods.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Not enough products are labeled gluten-free to primarily purchase them, in the grocery stores at least. I do frequent a few specialty stores that carry labeled "gluten-free" products but our budget and other family needs have me frequenting regular grocery stores for the bulk of our foods. This makes me do lots of meals from scratch, using fresh or frozen foods that are absolutely plain and then seasoning them myself.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Kozy Shack pudding, flours to make the flour mix to bake with, cereals.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes it does. I will purchase the "gluten-free" product.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I don't like second guessing my husbands health. I want to feel safe purchasing products that we can use and not worry about. A label saying, "gluten-free" would definitely influence my purchasing choices.

1. What does the term "gluten-free" mean to you?

Contains no gluten from wheat, rye, or barley; I like the 20ppm definition.

2. How do you identify foods that do not contain gluten?

I stay with mostly "close to the hoof" and "close to the earth" foods. When I purchase prepared foods in a specialty market, I rely on the manufacturers to label "gluten free" and take them at their word for it. I read labels in the grocery store and phone manufacturers for undefined items. It would be particularly helpful if all mfgs would label the source of items such as modified food starch. It would be extremely helpful if mfgs were to label "incidental" non-ingredients, such as flour used to dust production lines.

3. How much time do you spend identifying gluten-free foods?

WAY too much. I rely heavily on on-line sources and the findings of other celiacs who post regarding manufacturer responses.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

It would be helpful if mfgs would label for gluten free; I often patronize those who make it easy, such as Progresso soups, which now indicate the possibility of wheat (and other allergens) at the end of the ingredient list. I derive comfort and security from items labeled gluten free, but there are too few of them on the market to rely upon exclusively.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Hormel pepperoni, Thai Kitchen products. In specialty food stores, breads, baked goods (Whole Foods), flours, cereals, cookies, pasta.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

YES. I'm always glad to see it and make a point of purchasing those items.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

A small "GF" on the label, as with kosher labeling, would be fabulous. Although the laws seem to exclude gluten itself from the known allergen list, it would be very helpful if not only wheat but rye and barley (and oats, given the continuing controversy about its use for celiacs), as barley seems to come up often with caramel color, for example, and "malt" flavoring. It would also be helpful to know whether the item was produced on lines that also produce gluten-containing foods or in a plant that handles both.

1. What does the term "gluten-free" mean to you?

food free of wheat, barley, oats, rye.

2. How do you identify foods that do not contain gluten?

Check ingredients on labels. Don't buy questionable items, i.e. modified food starch, soy sauce, etc.

3. How much time do you spend identifying gluten-free foods?

I read labels all the time! Very time consuming.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Not necessarily. But that would certainly help. I don't usually purchase many packaged food items because there is too much room for error.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Bread, waffles, pizza, baked goods.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

YES!YES!YES!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Very helpful if food was labeled GLUTEN Free. Many companies I have called say "if wheat were used, it would be on the label." That is not good enough. I don't feel safe. Once I ate a cereal bar that I was told was gluten free (these were distributed at our celiac meeting). However, I read the label and it listed "malt" I called the company that they said malt was from rice! I talked to someone at the meeting who ate one of these bars and didn't feel well. Very confusing!

1. What does the term "gluten-free" mean to you?

Foods that do not contain gluten (but may contain a minimal level below a particular cutoff--20ppm I believe)

2. How do you identify foods that do not contain gluten?

By reading labels AND using information obtained from manufacturers and/or GF product lists

3. How much time do you spend identifying gluten-free foods?

A lot!!! Hours and hours overall. Maybe 30 min per shopping trip--more if I am using new products. Much more if I am checking out foods for camps, school functions, etc.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Yes. I do this whenever possible.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

crackers, english muffins, soups, cereals, frozen entrees (enchiladas, macaroni and cheese), cookies

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes. I need that reassurance that a product is really GF. I do not ever knowingly ingest gluten and my 18 year old son is just as careful as I am.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Yes. *I think that the need for accurate labeling is critical.* Ingesting even low levels of gluten over a prolonged period of time can have deleterious health effects in adults and particularly in children. It is very important for celiacs to obtain and absorb the vitamins and minerals that are required to maintain optimal health, growth and development. Most of our foods such as breads, pasta and cereals are not fortified like "regular" food are. This is an extremely unfortunate situation because the celiac population is **selectively vulnerable** to deficiencies in the very nutrients that are fortified BY LAW in regular products. Since even small amounts of gluten can damage our intestines so it is essential that we know if food contain gluten. It is very important to be sure that children and adults with celiac disease do not have subclinical or clinical vitamin, trace mineral, iron and calcium deficiencies. Accurate labeling can help us to make safer choices about food products. Many children are diagnosed with celiac disease during the critical period of brain development and it is essential that the foods they eat once they are diagnosed are gluten free. Folic acid, B12, B6, etc. have important roles in in DNA repair and methylation reactions and as cofactors in enzymatic reactions. Individuals with celiac disease do not just need gluten free food and accurate labeling. We also need mandated fortification of our foods to at least the same levels as the regular population!!!

I am a licensed nutritionist in the State of Maryland and have a Ph.D. in Nutritional Biochemistry from the University of Maryland College park. I have been doing research in brain development and neurochemistry for >25 years.

1. What does the term "gluten-free" mean to you?

It means not ingesting any foods with gluten in them such as wheat, barley, rye and oats.

2. How do you identify foods that do not contain gluten?

Wheat, barley, rye and oats

3. How much time do you spend identifying gluten-free foods?

Approximately 30 minutes each day, sometimes more when I travel.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I prefer "gluten free" but read all the labels and sometimes find items that are gluten free according to the ingredients.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Breads, baked goods, vegetables (packaged), packaged meats, sauces and spices, canned goods, snacks such as potato chips, nuts, corn chips, drinks and drink mixes, candies, gum, mints, toothpaste, shampoo, skin care products, makeup, coffee, tea,

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely, makes me feel safe to purchase items labeled gluten free and saves lots of time.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

I would like to see everything that could have gluten in it listed in the ingredients. I especially like the labels that list "allergens" as it saves time and ensures that we know it is safe if all the allergens are listed. Things like "modified food starch" should be more definitive, list what the starch is such as wheat or cornstarch or bean flour, etc.

Q1. Gluten-free means that the food contains none of the grains associated with gluten, nor is there substantially any chance that the food has been cross-contaminated by processes that may have had ingredients manufactured with grains containing gluten.

Q2. First, I always look at the labeling to determine if any of the ingredients are suspicious for gluten, including those packages that specifically indicate that the product is gluten-free. Second, if I have any doubts, I always contact the manufacturer to confirm that the product is gluten free, including searching manufacturer web sites.

Q3. It is difficult to assess how much time I spend identifying gluten-free foods, but I believe I have spent many hours over the past year doing so, including searching web sites and other sources of information.

Q4. This is a poorly worded question. If you mean do I ever purchase foods that are specifically labeled gluten-free, the answer is absolutely yes. However, I also purchase many products that are not specifically labeled gluten-free, although it would obviously be my preference to have them so labeled.

Q5. Cereals; snack foods, such as candy, chips, etc.; frozen breakfast foods, such as waffles.

Q6. Gluten-free labels do influence my purchase decisions.

Q7. It is especially important to identify the sources of "natural" and/or "artificial" ingredients, since I have found that a number of products containing "natural" ingredients actually contain barley malt as a flavor enhancer. I also believe it is important for medicines and certain cosmetic products such as lipsticks to be labeled as to the gluten content. We know for sure that certain pharmaceutical products contain gluten when used as a binding agent. Also, for us women, lipstick products are easily ingestible. If you have ever tried to decipher the ingredients list on a tube of lipstick, you know you have to be a chemist to figure it out.

1. "Gluten-free" means it has no ingredients derived from wheat, barley, or rye and that it has not been cross-contaminated by products with these ingredients.

2. Shop for foods that specifically say "gluten free" (usually at health stores), read labels for hidden gluten sources, and call the manufacturer and hope the \$7/hour telephone person knows what to look for.

3. Currently very little; I know what to look for and where to find it. When I was first diagnosed, I spent a lot of time looking for stores carrying gluten-free products.

4. Yes.

5. Breads/pastas/cereal, soy dairy products, condiments

6. Yes. Those with a "gluten-free" label indicate that the manufacturer is aware of the problem and has made an effort to avoid

cross-contamination (I hope).

7. I like labels that have an allergy indicator immediately below the ingredients list --i.e., "warning: contains/processed on machinery that also processes wheat, peanuts, tree nuts, casein, dairy...." -- or clearly indicates that it is "safe/suitable for: vegetarians, vegans, celiacs...."

1. What does the term "gluten-free" mean to you?

Gluten-free means the food product contains ingredients that are free of gluten AND have been prepared in an environment that is free of gluten.

2. How do you identify foods that do not contain gluten?

1) Look for labeling, "Gluten-Free" (and these days one does have to scrutinize the entire box as there's no standard in labeling).

2) Look at the ingredients to discern if any contain gluten

3. How much time do you spend identifying gluten-free foods?

More than I care to. To quantify, I'd say my grocery shopping time has increased 50% because of the need to scour stores for gluten-free foods (there's not always a dedicated section) and to scrutinize packaging.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Yes -- primarily not exclusively. There are some products that I know to be gluten-free because I've contacted the manufacturer. But even then, ingredient lists change from year to year, requiring the process identified in #2 all too often.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Bread. Frozen waffles. Cookies, crackers, snack bars. Frozen dinners (Amy's).

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely. I will always go with a known gluten-free food over a questionable product. This is my health and longevity we're talking about!

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Food manufacturers know whether their product is gluten-free or not. There is a fairly wide selection of gluten-free foods that are not labeled (just look at the list produced by Whole Foods Stores or Trader Joe's). So, the need & practice of labeling foods gluten-free is simply a matter of updating labeling -- something a manufacturer most likely reprints every six or 12 months anyway. We're not asking to change their manufacturing process; just their labeling. It's really quite simple and given, advanced notice, would not create a negative financial impact to any manufacturer.

1. What does the term "gluten-free" mean to you?

Absolutely no gluten in the product.

2. How do you identify foods that do not contain gluten?

Read labels and contact manufacturers.

3. How much time do you spend identifying gluten-free foods?

Hours reading every label for everything I put into or on my mouth.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

When possible, but so little is labeled that way, even in the health food stores.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Anything I can locate (breads, crackers, dairy, anything that is pre-packaged).

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes, absolutely. I feel safer.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

We need this desperately. A "quick" trip to the supermarket should not take two hours plus calling manufacturer after I get the product home. Let alone returning product purchased after manufacturer refuses to state it is gluten free or what the possible gluten containing ingredient even is. Many manufacturers err on the side of caution and still refuse to call an item gluten free based on decades old knowledge that we now know is not accurate (i.e. vinegar, distilled alcohol, starch, maltodextrin). I know the last two are from corn, but if I cannot get the manufacturer to tell me which item is of concern to them, how can I know for sure the item is gluten free?

1. What does the term "gluten-free" mean to you?

Free of wheat, barley, oats and rye, in both ingredients and preparation.

2. How do you identify foods that do not contain gluten?

By reading labels. If the food appears to be gluten-free I double-check with the manufacturer. If it says gluten-free on the label I feel safe.

3. How much time do you spend identifying gluten-free foods?

Every time I food shop I recheck labels since ingredients change. Every time we eat out.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

I am more likely to buy something repeatedly if it is labeled gluten free, but some staples are part of our regular shopping trips and I buy them knowing they are GF.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Pasta, soup, baking mixes, breads, salad dressing, frozen food, cereals.

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Absolutely. Aside from feeling that the food is safe, I want to support a company that cares enough to label responsibly. I will always choose a product labeled GF over one that is not.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

By mandating laws about labeling and making it easier to identify foods that contain (or do not contain) gluten, you would be adding tremendous quality of life for those families dealing with a gluten intolerance. There is nothing more paralyzing than the fear that you, as a parent, cannot safely feed your child. Labeling makes a huge difference. It is incomprehensible to me why a company would continue to list an ingredient such as modified food starch when they could take responsibility and specify the source.

1. What does the term "gluten-free" mean to you?

Gluten free means that I cannot have any foods with any gluten in them or else I will get very sick....short term and long term sick. Gluten free is how I'll be for the rest of my life. It is actually a healthier way of living, but can be difficult because of the food products that are not clearly labeled.

2. How do you identify foods that do not contain gluten?

I call the 800 number (if there is even a number) on the package while I'm walking through the grocery store. Often times they are closed, they won't guarantee, or they can't answer my question. It will be nice to have labels clearly marked on EVERY package. Just because we have an intolerance does not mean that our shopping should be any more difficult than someone without a food intolerance.

3. How much time do you spend identifying gluten-free foods?

Too much time.....you can never tell with all of the additives and artificial flavors, starch, etc. A lot of labels are unclear and difficult to read. Kraft has done a great job being specific and accomodating to allergy needs. (Obviously gf manufacturers have done the same).

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

The breaded or floured foods, I usually buy when I see gluten free on them. For example the waffles (VANS I believe) clearly say gluten free. Amy's frozen meals are clearly labeled. Frozen potatoes, I choose the ones that say gluten free, opposed to Ore Ida that do not label them. I also buy the Lay's products that list if it contains wheat.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Breads, potatoes, frozen meals, meal supplement bars, soup, broth, cookies, canned vegetables, polly-o string cheese

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes it does. If the label says "gluten free" I buy that item. It is important to know and feel reassured that I definitely will not get sick when I'm eating. Seeing GF on packages makes me want to buy that product. I am starting to see it more and more...even at friends' houses who are not gluten free when they're trying to figure out what I can eat, I'll see a food product labeled gluten free. They're amazed that it says that on there and I'm happy because I have something "safe" to eat.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

Celiac is not just simply a diet that we're trying to follow, we HAVE to follow it for health reasons. Who wants to end up with intestinal cancer because of mislabeled or unclear labeling on food products? It's already frustrating enough to find out you can never ingest anything with gluten again...trying to weed through the labels and products, making phone calls in the middle of the store, and still leaving without an answer is discouraging, and I personally have stopped buying certain products because companies are not willing to guarantee their products are gluten free. In today's world, allergies are not uncommon and manufactures need to be aware of this, and more accommodating.

1. What does the term "gluten-free" mean to you?

There is no glutinous grains used in the manufacturing of the product and that there is no chance of cross contamination with other products containing gluten.

2. How do you identify foods that do not contain gluten?

Read labels very carefully and thoroughly and if not sure, call or contact the company to check and double check.

3. How much time do you spend identifying gluten-free foods?

An awful lot of time at the store, researching companies and calling/contacting through phone or email.

4. When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled "gluten-free"?

Most of the time. Sometimes will we purchase foods that do not contain gluten, ie: potato chips, but are processed in a facility that processes other foods that contain gluten.

5. If so, what types of packaged foods that are labeled "gluten-free" do you purchase? For example: breads, dairy foods, canned vegetables?

Breads (frozen) , cookies, cakes/muffins, brownies, pretzels, snack type foods

6. Does a "gluten-free" label influence your purchasing decision when you have a choice among products having identical ingredient lists?

Yes, because I feel reassured that some testing has been done on the products to ensure the quality of the gluten free label.

7. Would you like to share any other thoughts about the need for accurate, understandable food labeling, or your experiences with food labeling?

It needs to be as clear and concise as it can be because the general population reads only around an 8th grade level (and that is pushing it!). Most people are not savvy enough or educated enough to make good choices.

The labeling needs to include whether or not the product is produced in a facility that manufactures other products with wheat, rye, and barley so one can make an informed decision...to buy it or not. Frankly, I do not buy items that share that warning because I am taking a chance of feeding myself and my children potentially harmful food. Is that a risk that I want to take? NO, when it comes to your children, you need to be as careful as you can be and as informed as you can be. If celiac disease were an allergy that affected breathing and you needed an epi-pen to save your life, then a warning on the labels would be life saving, in an immediate sense. It is just that the symptoms are so varying among individuals and some are symptom free is exactly the reason that the labels need to be as stringent as possible.

What does the term gluten free mean to you?

For a long time, I thought gluten-free meant exactly that - that the food had absolutely no gluten in it. It never occurred to me that a food labeled gluten-free could possibly have any gluten in it. If I read the ingredients, there was nothing that could possibly contain gluten. I wasn't really thinking about cross-contamination of gluten-free foods. I really thought gluten-free foods were the safest for my daughter. Since then, of course, I have learned a lot more about what the term means. It throws me a bit to think that one of the biggest threats to her might be a food that she eats consistently, every day, in rather large quantities in part because it is a gluten-free substitute for "regular" foods. But I try to be realistic when assessing what gluten free means and how much of a threat a regularly consumed gluten-free food is. I am comfortable that my daughter can safely eat the gluten-free food that is available.

How do you identify foods that do not contain gluten?

I read the ingredient label or I go by a label that says gluten-free on the package, followed by a reading of the ingredient label. I do not rely on lists of gluten-free food anymore.

How much time do you spend identifying gluten free foods?

Even 13 years after my daughter's diagnosis, I would estimate that about 30 percent of any shopping trip is spent reading labels to determine if something is gluten free. That means if it takes me 2 hours to shop, about 40 minutes is devoted to reading labels.

When you purchase packaged foods, do you purchase foods that are primarily or exclusively labeled gluten free?

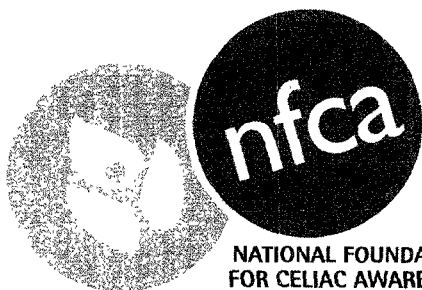
No, I also purchase regular foods from the grocery after reading the label and determining that they are gluten free. I do rely on certain products that are labeled gluten free, like bread, pasta, cake mixes etc. Mainly I buy the things that could not be gluten free unless they were specifically made to be so.

Does the gluten free label influence your purchasing decision when you have a choice among products having an identical ingredient list?

It is always helpful to have a gluten free label. For example, Uncle Ben's white rice is labeled gluten free. I can tell it is gluten free by reading the ingredients, but its just nice to have it be made so simple when managing the diet can be complex. Plus I think it helps make you feel less isolated and odd when a mainstream product carried in a regular grocery is labeled gluten free.

Other thoughts?

What I mainly want from a food is availability for my daughter. What I really want is food companies that will go the extra step to make a product gluten-free if its possible. For example, rice cereal makers who would be willing to use a flavoring other than barley malt that renders a product that should be gluten free unusable. But I suppose I'm dreaming. What I want from labeling is a clear picture from the label as to what is safe. I don't want a label that makes me think something might not be safe when it actually is, for example a product that contains citric acid made from wheat when, in fact, citric acid made from wheat is still gluten free. I don't want a label that says a food contains wheat when the amount is too small to cause damage. I don't want a label on something that contains spelt that says the product is gluten free. I would like a gluten free label that holds companies responsible for testing their products to be sure they do not contain amounts of gluten that are over acceptable levels. (currently thought to be somewhere around 20 ppms)



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August 19, 2005

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RE: Docket Number 2005N-0279

The National Foundation for Celiac Awareness is submitting herewith written comments regarding gluten-free labeling of food.

Enclosed are two copies of the comments presented by Alice Bast, Executive Director of the National Foundation for Celiac Awareness at the public meeting held on August 19, and the supporting survey data referenced in her comments.

If you have any questions or require additional information, please contact me at 215-325-1306.

Sincerely,

Diane Frances